



## Abstract

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**PI Title:**

**Project Title:** People with Chronic Illness and Advance Directives

**Abstract:** *An advance directive (AD) is a written statement by patients about how they want medical decisions made and/or whom they want to make decisions when they can no longer make them for themselves. Federal law requires patients be told of their right to complete ADS. Studies show that fewer than 20 percent of the US population has completed ADS. The purpose of the study, in the application under consideration, is to investigate end of life decision-making from the perspective of people with chronic illness particularly concerning: the completion of ADS, the meaning of ADS for them, and their experiences with, attitudes toward, and perceived needs related to ADS. The primary aim of the study is to: Determine the perceived needs of persons with chronic illness related to ADS. The secondary aims are to: Understand how the perceptions of end of life (EOL) care influence the perceived needs of persons with chronic illness related to ADS; elicit the meaning of ADS from the perspective of persons with chronic illness; describe their experiences with and attitudes toward ADS; and provide insight into the ways health care providers can assist chronically ill patients with EOL decision-making and completion of ADS. Sixteen individual interviews and 8 focus groups will provide the narrative data. In addition 2 focus groups will be used to verify the analysis. Approximately 80 participants will be recruited from support groups representing a variety of chronic illnesses. Data will be analyzed using the constant comparative method of grounded theory. It is expected the results of the study will yield theoretical models that explain the meaning of ADS and the experiences and needs of people with chronic illnesses regarding ADS. The study proposed in this application is a natural progression in my program of research related to ADS. My previous studies and this proposed study of the perceptions of people with chronic illnesses regarding ADS will provide me with understanding and insight to design an intervention*

*study (Long Term Objective) that will facilitate AD decision-making for persons with chronic illness.*

***Thesaurus Terms:***

*chronic disease /disorder, decision making, health behavior, health related legal attitude, experience  
human subject, interview*

**Institution:** STATE UNIVERSITY OF NEW YORK AT BUFFALO  
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